

**Nebraska Early Hearing Detection and Intervention Program**  
**Advisory Committee Meeting**  
**September 11, 2014**  
**Minutes**  
**1:00-4:15**



Riverview Lodge, Eugene T. Mahoney State Park

**Attending:**

**Members**

Nina Baker  
Kathy Beauchaine  
Amy Bunnell  
Linsay Darnall, Jr.  
Rhonda Fleischer  
Kim-Jae Kang  
Rick Kang  
Charlie Lewis  
Stacie Ray  
Colleen Richart  
Susan Stibal  
Heather Witte  
Renee Zimmerman

**Guests**

Kelly Brakenoff-Interpreter  
Jamy Elker-Interpreter  
Sam Meisels  
Mary Pat Moeller  
Jennifer Racine  
Cole Johnson

**Staff**

Jim Beavers  
Melissa Butler  
Kathy Northrop  
Debie Seiler

**Newborn Screening**

**Blood Spot Staff**

Krystal Baumert

**Meeting start time** – The meeting was called to order by Committee Chair Kathy Beauchaine at 1:00 pm.

**Open Meeting Act** – Presented at the beginning of Advisory Committee Meeting by Kathy Beauchaine.

**I. Welcome and Introductions**

Kathy Beauchaine, Advisory Committee Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests.

**II. Review of Agenda**

Kathy Beauchaine recommended that Dr. Sam Meisels give his presentation before the meeting minutes are reviewed and approved. The Committee members agreed.

**III. Presentation - Buffett Early Childhood Institute**

Dr. Sam Meisels is the founding executive director of the Buffet Early Childhood Institute. Prior to his work with the Buffet Early Childhood Institute, Dr. Meisels served as president of Erikson Institute from 2002–2013 and also worked at the University of Michigan, where he was a professor and research scientist.

The Buffet Early Childhood Institute was established in 2011 by a gift from Susie Buffet and has been operating for over one year. Dr. Meisels presented information about the Buffet Early Childhood Institute's history, research, and findings in the area of early childhood development as it relates to education, literacy, family intervention, and health and behavioral issues. Dr. Meisels also presented information about the goals of the Buffet Early Childhood Institute, with the primary goal being the development, testing, and replicating of initiatives on childhood learning and implementation of research-based practices and

evidence-based solutions to improve the lives of children from birth through age eight. Dr. Meisels then entertained questions from the Advisory Committee members including discussions on the provision of services and addressing the needs of children who are deaf or hard of hearing.

#### **IV. Review of Minutes**

The minutes from the June 11, 2014 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting and printed copies were available upon request at the meeting. A motion to approve the minutes as published was made by Rick Kang; seconded by Nina Baker and unanimously approved by the Committee members.

#### **V. Hearing Aid Bank/HearU Nebraska Update**

Stacie Ray provided the quarterly report for HearU Nebraska and reviewed the information detailed in the handout. The handout is included in the handouts packet. Stacie also informed the Committee that HearU Nebraska applied for and received a grant from *Women Investing in Nebraska*; the grant will be awarded on September 25, 2014.

#### **VI. Amplify Presentation**

Susan Stibal presented information on the parent group *Amplify*, which is a support group for parents of children with hearing loss. The group is based in Lincoln, Nebraska, but serves families around the state who are interested in family support. *Amplify's* goals are to support families through their children's hearing journeys and collaborate on important issues related to hearing loss. Susan also stated that *Amplify* is working on becoming an AG Bell Chapter. AG Bell Chapters work to increase awareness of hearing loss and the benefits of early intervention.

MeLissa Butler added that the purpose of having Susan present information on *Amplify* was to determine if the Committee agrees that the Amplify flier should be added to the Parent Resource Guide. The Committee agreed that the *Amplify* flier should be included.

#### **VII. New Member Orientation Manual**

Debie Seiler presented the New Member Orientation Manual that was compiled by Pete Seiler, Matthew Theilker, Lindsay Darnall, Jr., and herself. Debie asked the Committee to review the manual and make recommendations for updates, changes, and corrections.

Colleen Richart commented that she liked page 17 which talks about Deaf community representation and the *Medical Model vs. Socio-Cultural Models*. She said this shows that the Committee is progressive and open-minded about social issues related to the Deaf culture. Kathy Northrop commented that some people felt the information presented on this page may be offensive to those in the medical community. Kathy Beauchaine added that she felt it was useful information to include, because some new members may not be aware of the Deaf community or issues that have come up in Advisory Committee discussions. Steve Boney commented that if the manual is going to represent a variety of communication options this information should be included for awareness and educational purposes. The Committee was in favor of keeping the information on page 17 as part of the manual.

Debie also added that she will be updating the *Resources* page and she is open to suggestions regarding what information should be included. Kim-Jae Kang recommended that statewide and national resources be included. Colleen recommended an electronic version of the manual be available for members. Debie stated that it will be available both ways. Nina Baker recommended that any organization listed should have contact information included.

Kim-Jae recommended that communication modalities should be added to the *Definitions & Terms* section on pages 19-20 or be included in the *Acronyms & Abbreviations* chart on page 21. Lindsay added that on Page 18, the first paragraph should state that all deaf people can't read lips, as this is a common misconception among hearing people. Kim-Jae also felt that the *Definitions & Terms* should be in a logical order rather than alphabetical order. Debie asked that Kim-Jae email her suggestions of what a logical order should be. Debie stated that any other recommendations can be sent to her via email. The manual will be revised and reviewed again at the December 11, 2014 meeting.

#### **VIII. Workshops – Debie Seiler**

Debie Seiler stated that the NE-EHDI Program is planning to collaborate with Hands & Voices and the four Regional Programs for Students Who are Deaf or Hard of Hearing on Parent Workshops in the spring of 2015. Ideally, two will be held in March, one in Gretna and one in Kearney, and one will be held in May in Scottsbluff. They are hoping to have Karen Putz present at all three workshops. Debie added that Karen is a barefoot water skier, writer, speaker, and a Deaf woman. Debie recommended that everyone visit her website and read her story at [www.karentputz.com](http://www.karentputz.com).

Lindsay Darnall, Jr. asked about Roots & Wings. Kathy Northrop stated that the NE-EHDI Program's involvement in the funding and planning of the Roots & Wings Parent Weekend was very limited this year, as it was mostly funded by Part C through the Nebraska Department of Education. The NE-EHDI Program provided \$5,000 which paid for the deposit at The Lied Lodge. Rhonda Fleischer will attend representing the NE-EHDI Program. The event will be held at The Lied Lodge in Nebraska City the weekend of September 26-28, 2014. Contact Theresa McEvoy at Boys Town if anyone has questions or wants further information.

#### **IX. Hands and Voices – Jennifer Racine**

Jennifer Racine, President of the Board of Directors of the Nebraska Chapter of Hands & Voices, presented information on the program as detailed in the handout. Kathy Northrop asked if there were membership dues. Jennifer stated that there are dues, it is \$25 for families and \$40 for professionals. She added that in the event that a family cannot afford the \$25 fee, membership would not be denied because they don't want to prohibit families who need support from being members. Kathy N. asked if Hands & Voices has to pay dues to the national organization. Jennifer said that yes, they do pay dues to the Hands & Voices national organization. Kathy N. also asked if Hands & Voices does any fundraisers. Jennifer said that Hands & Voices does host several fundraising events throughout the year. Rick Kang recommended that when Hands & Voices hosts family events, they encourage the families to invite their Primary Care Physician or Pediatrician so those professionals can interact with families and children who are deaf or hard of hearing. The interaction and firsthand experience with these families would leave quite an impression, as Primary Care Physicians and Pediatricians have limited contact with children who are deaf or hard of hearing. Renee Zimmerman agreed, stating that awareness among Primary Care Physicians and Pediatricians is important because parents trust them to provide guidance and recommendations.

#### **Update on NE-EHDI Web Site – Kathy Northrop**

Kathy Northrop stated that the NE-EHDI web site is not live yet. There are copyright issues surrounding graphics but, hopefully, this is the last roadblock.

#### **X. Audiology Services Concerns**

MeLissa Butler shared that there is concern about the availability and quality of pediatric audiology services in western Nebraska and asked the Committee members if they have any suggestions as to how we can get quality pediatric services out there. The following recommendations were made:

- Satellite Clinics – Research the possibility of any local audiology facilities opening a satellite clinic in that area.
- Professional Outreach – Invite audiologists from western Nebraska to come to the Advisory Committee meetings in an effort to raise awareness about the special needs of pediatric audiology.
- Teleservices – Dr. Michelle Hughes, at Boys Town has a large grant which is funding opportunities to incorporate teleservices throughout underserved areas in Nebraska. There may be an opportunity to collaborate with her on providing teleservices out in the western part of the state.
- Mobile Hearing Screening Booth – Students or volunteers can drive equipment out and provide services to underserved areas.
- Outreach Services – Collaborate with Buffet Early Childhood Institute to help with funding to reach out to that area of the state.
- Collaboration with the Public Schools – Rhonda Fleisher stated that the schools have much better technology in the western part of the state than any other part of the state, so perhaps there could be some assistance with the school programs.
- Collaboration with Part C – Part C has a planning section that addresses gaps and barriers.

The Committee agreed that there needs to be quality pediatric audiology services available to families in western Nebraska, whether that means sending someone out there or helping families with transportation to access services elsewhere. Nina Baker recommended that Kathy Northrop address the issue with Planning Region Team 13. Nina will send Kathy N. the contact information.

## **XI. Quality Assurance Reports**

Jim Beavers presented the most recent Quality Assurance Reports that are sent to hospitals semi-annually. MeLissa Butler pointed out that the language has been updated based on the discussion that took place at the March 12, 2014 meeting where the Committee had discussed use of the terms “hearing loss” and “normal hearing” and how many in the Deaf community they feel that these are negative terms. At that time, the Committee agreed that rather than “Normal Hearing”, “Confirmed Hearing” could be used. In place of the term “Permanent Congenital Hearing Loss” the term “Confirmed Deaf or Hard of Hearing” could be used.

Rick Kang stated that he feels that the term “Confirmed Hearing” is not accurate. The Committee discussed other terms that could be used. The term “no further testing” is clear but it is not accurate. Some members feel that we should not say “passed” because that implies that the deaf or hard of hearing infants “failed” the hearing screening. They also feel that we should not use the term “normal”, because that implies that deaf or hard of hearing infants are “abnormal”. Steve Boney recommended that the NE-EHDI Program survey the hospital staff who interpret these reports to see what the term “confirmed hearing” means to them. Do they understand what information is being conveyed? Rick Kang stated that he feels that if this is a medical report going out to medical professionals, then medical terminology should be used. He also stated that he understands that in social situations it is appropriate to use socially acceptable terms. However, everyone needs to use terminology that is appropriate for the audience that is being addressed.

Nina Baker pointed out that “mental retardation” was a “medical” term that had to be fought to have removed from all medical and socially acceptable language, so she feels that it is important to keep looking for new words, new terms that everyone can feel okay about.

Stacie Ray commented that she felt the Committee members needed to spend much less time discussing issues such as terminology and that it seemed to take up a lot of time at some of the meetings. Instead, she added, the focus of this Committee is to help families of children who are deaf or hard of hearing. Several members agreed that the time spent discussing which words to use was sometime excessive.

**XII. 2013 Newborn Screening and NE-EHDI Annual Report**

- XIII.** Kathy Northrop informed the Committee that a copy of the *2013 Newborn Screening and NE-EHDI Annual Report* was included with the handouts. Members of the Advisory Committee can review the report and contact her with any comments or feedback.

**XIV. NE-EHDI Statistics and Lost to Follow-up Information**

Jim Beavers briefly reviewed the handouts entitled *January-June 2014 DOB Status Report* and *Nebraska "Lost" for DOB 2007-DOB 2013*.

**XV. Other**

- Kim-Jae Kang announced that the *Center for Childhood Deafness* is holding a fundraiser on Thursday October 16, 2014 and everyone is welcome to attend. Last year the proceeds went to the purchase of FM systems and iPads.
- Debie Seiler shared that Deaf Awareness Week is September 21<sup>st</sup> – 27<sup>th</sup> 2014, and that today is Interpreter Appreciation Day.
- Krystal Baumert also shared that September is Newborn Screening Month.

**XVI. Adjourn**

A motion to adjourn the meeting was made by Rick Kang and seconded by Rhonda Fleischer. The meeting was adjourned at 4:14 pm

*Next Meeting – December, 11 2014 – **1:00 pm** at Mahoney State Park, Riverview Lodge*

2015 Meeting Dates:

- March 19, 2015 (changed from March 12, 2014 due to EHDI Annual Meeting)
- June 11, 2015
- September 10, 2015
- December 10, 2015

Respectfully submitted by McLissa Butler, Community Health Educator